
“I am just terrified of my future” – Epistemic Violence in Disability Related Technology Research

Anon Ymous

University of Somewhere
Too many places

Katta Spiel

KU Leuven || Universität Wien
Leuven, BE || Vienna, AT
katta.spiel@kuleuven.be

Os Keyes

University of Washington
Seattle, WA, USA
okeyes@uw.edu

Rua M. Williams

University of Florida
Gainesville, FL, USA
williams2020@ufl.edu

Judith Good

University of Sussex
Falmer, UK
j.good@sussex.ac.uk

Eva Hornecker

Bauhaus Universität Weimar
Weimar, DE
eva.hornecker@uni-weimar.de

Cynthia L. Bennett

Carnegie Mellon University
Pittsburgh, PA, USA
cbennet2@andrew.cmu.edu

Abstract

Technology for disabled people is often developed by non-disabled populations, producing an environment where the perspectives of disabled researchers – particularly when they clash with normative ways of approaching accessible technology – are denigrated, dismissed or treated as invalid. This *epistemic violence* has manifest material consequences for our lives as disabled researchers engaging with work on our own states of being. Through a series of vignettes, we illustrate our experiences and the associated pain that comes with such engagement as well as the consequences of pervasive dehumanization of ourselves through existing works. Our aim is to identify the epistemic injustice disabled people experience within HCI, to question the epistemological base of knowledge production leading to said injustice and to take ownership of a narrative that all too often is created without our participation.

Author Keywords

Disability; Epistemic Violence; Epistemic Oppression; Accessibility; Cripistemologies

CCS Concepts

•Human-centered computing → Accessibility theory, concepts and paradigms; Interaction design theory, concepts and paradigms; •Social and professional topics → Disabled people;

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.
CHI '20 Extended Abstracts, April 25–30, 2020, Honolulu, HI, USA.
© 2020 Copyright is held by the owner/author(s). Publication rights licensed to ACM.
ACM ISBN 978-1-4503-6819-3/20/04 ...\$15.00.
<http://dx.doi.org/10.1145/3334480.3381828>

As Disabled Scholars

As disabled scholars¹, we find strength in community and share deep bonds with each other. Within these communities, there is fierce loyalty. There is a strength within that seems dangerous to the outside. We are unruly bodies², classified by society into a plethora of interlocking sets of dysfunction and disorder – because our neurology and our physiology cannot be contained into normative expressions by medicine, by discipline, nor even by our own shame. Though, when it comes to academia, we see a lack of representation [7] and a lack of conditions enabling us in taking part in scholarship with self-determination [24].

As disabled scholars researching, our experiences, particularly when researching technologies within the context of our own conditions, share peculiar commonalities. Be it around physical, sensory, cognitive, or psychological conditions, we find ourselves represented in the literature as objects of inquiry – systematically belittled, disregarded, ignored and dehumanized. Despite several calls for the inclusion of disabled people in technology research about them [30, 48, 54], work that claims inclusive methods continues

¹This identity is not shared by all authors. While most self-describe as such, some prefer to refer to their identity “as neuro-diverse (and from this sometimes being disadvantaged and getting disabled)” (personal correspondence). We chose the language within this article politically [2]. However, it is fundamentally necessary to attend to dissenting positions (also within our group) and acknowledge individual preferences.

²In using this particular language, it is paramount to acknowledge that all authors of this piece are white and—at least currently—employed and funded. Subsequently, we hold a significant amount of privilege within the disabled community, which is largely not even considered part of “the work force” [32]. We might be unruly, but we have been able to parlay our whiteness for access to spaces that more violently exclude our BIPOC peers [17]. We take the limitations that come with our partial perspective [21] as well as the privilege that entails seriously. Please consider reading up on works by disabled BIPOC scholars, e.g., Theri Alyce Pickens (e.g., [41]), Lydia Brown (e.g., [6]), Karen Nakamura (e.g., [38]), Sami Schalk (e.g., [45]), and more (e.g., [15, 23, 37]).

to distance disabled people from the shared construction of knowledge through tokenistic forms of “voice”³ that fail to redistribute power and agency to disabled people [4]. Instead, disabled people are often persistently excluded from making meaning about technologies presumably for them [50]. Such epistemic exclusion allows the circulation of implicit bias against disabled subjects as producers of knowledge. Privileging, for example, neurotypical perspectives on neurodivergent needs [49], demarcating the space for technologies almost exclusively to domains of cure, therapy and intervention – all of which are tied to rhetorics removing the intricacies of disabled lives from the range of human experiences [11, 52].

As disabled scholars navigating the academy, we find ourselves related to by our non-disabled peers as a problem, needy, difficult, unruly. We face disbelief in light of our diagnoses (“You don’t really look autistic!”, “How did you get through school with ADHD?”, “Dyscalculia isn’t really a thing, you know?”, “I never would have thought!”), dismissal of access needs as too costly, our complaints⁴ being framed as aggression and continuous erasure of our situated, lived expertise as “too much” (“You have to be more appreciative about what came before.”, “We are just learning about all of this!”, “You’re so emotional!”, “If this is a persistent issue for you, maybe the issue isn’t other people.”).

As disabled scholars researching our own conditions, we are deeply hurt. We read about ourselves as disordered, as an emotional, financial and overall burden to the people around us, as incapable of forming social relationships,

³A use of “voice” that often fails to acknowledge the intricate issues involved, particularly when voice (understood as expression of agency) is rarely recognized when not facilitated through speech (see also, [3]).

⁴This term should be understood with Ahmed’s “Complaint Biography” in mind [1], particularly as “statements that are not intended as complaints can be received as complaints” (p.515).

undesirable, less than, limited, incapable, as fundamentally lacking—echoing the worst nightmares of our internalized ableism [10]⁵. The texts are full of the “language of the helping professions” [16]; even though we assume that authors do mean well, those who do not position their work to disability as politicized may be subscribing to a notion of doing good, while not realizing and reflecting that what is allowed to be understood as “doing good” is reliant upon entrenched sociocultural traditions of ableism⁶.

As disabled scholars, we say this, (pain)fully acknowledging that we have, in previous publications and inadvertently, done our fair share to uphold this system ourselves, and acknowledge that we cannot claim to be free from doing so with this piece or any in the future. This issue goes beyond individual blame, it persists as a systemic cultural bias that seeps into academia which is dominated by Western positions [8]. Even as unruly parts of the system, we find ourselves complicit in holding it up, sometimes to survive it, but still often simply because we have not yet disentangled ourselves from hegemonic understandings of “doing good”. Yet, we are hurt. Our (becoming)⁷ disabled beings seem to splice our human selves.

⁵Ableism is “a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human” [9, p44]. Internalized ableism is then a form of “epistemic invalidation: to make disabled people not know themselves” [20, p640].

⁶This is somewhat parallel to how “doing good” has been previously critiqued in connection with colonialist design tendencies [39].

⁷We deliberately do not intend to disentangle the myriad of tensions related to how disability can be conceptualized along different models and experienced (and/or attributed) as external and/or internal. However, we do acknowledge that technologies have a particular role to play in the negotiation of presumed disabilities, abilities and capabilities [36].

Knowing about Violence

When people discuss violence, they often mean material violence. Cutting, hurting, harming; *reducing*. Making someone less of a person. They often separate the discussion of such violence from the acts of violence described.

Epistemic violence is violence against one’s status as a *knower*; one’s role as a creator and communicator of knowledge. It is the dismissal of people as credible sources of information, because of our presumptions about them, or because of how their communicative means (or what they have to communicate) clashes with how we would like to believe the world works. When the fervent critic of colonialist modes of knowing, Spivak, asked “can the subaltern speak?” [51], she was referring to epistemic violence – she was not asking literally whether the subaltern can speak, but whether anyone would listen. And whether, in an orchestra of silence, the subaltern would bother continuing. The boundaries on who is acknowledged and attended to as a knower are, hence, fervently drawn on several accounts, disability being just one of them, whereas all of them, like the undisputed acts of violence exemplified above, have fundamental material consequences.

Extending Spivak’s work, scholars such as Fricker, Medina and Dotson have articulated ideas of epistemic *injustice* and epistemic *violence*: harm done when one’s status as a knower, and, consequently, one’s personhood, is denied and delegitimized [14, 19, 33]. We argue that disability demarcates a type of knowing and lived experience that is systematically subverted (see also, [31]). Disabled ways of knowing and disabled researchers are often marginalized away from “real” research deemed to produce the appropriate kinds of knowledges and the way that disability is frequently taken to identify someone as not only incapable of testifying as to themselves, but as to *anything* [46].

The Autistic Self Advocacy Network (ASAN), joined with other disability organizations to form the first annual [Disability Day of Mourning](#) in 2012. Since then, over 700 people have become part of the litany of our dead – disabled children and adults murdered by their family or caregivers. Over 100 deaths have been [logged in 2019 alone](#).

[On November 28th, 2018](#), Max Benson, an autistic adolescent, was held in a prone restraint by his teachers for over an hour. He became unresponsive during the restraint, but the staff believed he was “faking” being asleep in order to be released. He died the next day.

[Earlier that year](#), four-year-old Je’Hyrah Daniels was dragged from a car and thrown into the Hillsborough River by her mother. She drowned. Nine months prior, the mother posted a Go-FundMe asking for money to help her purchase therapeutic equipment after Je’Hyrah was diagnosed with autism.

But epistemic violence begins by rejecting that separation with an understanding that knowledge – the circumstances of its creation, circulation, and credibility – has power and material consequences [18]. As disabled people, people whose lives are often shaped by the knowledge others insist they have about the “truth” of who we are and how we live, we know this all too well. And if knowledge has material consequences, as it does in the social spaces we write in (e.g., by setting priorities in research funding [40]), then the treatment of knowledge and who counts as someone producing valid knowledge has consequences.

The treatment of knowers has consequences. For our materiality – and by extension, our personhood. In a society defined by an insistence on universalizing rationality that rejects the specificity of the knowing of disabled bodyminds [11], we cannot know, or our knowledge cannot be taken seriously. Hence, our knowledge and critique is dismissed without much consequence. It is improper.

We draw out what epistemic violence can mean for disabled researchers within the HCI community as we are required to explain the nature of our own oppression, over and over, hoping that eventually we will say it in a way that you will believe [5]. Each of the vignettes in the following section is written by a disabled community member, and each is anonymized (or not) according to author preferences⁸. They demonstrate both the breadth of what epistemic violence can be (in regard to the types of events and actions), and how they comprise various contingencies (material, bodily,

⁸We need to acknowledge the many researchers who cannot share their experiences here both because disability is figured such an undesirable experience they do not, cannot, or will not know they can identify with or even name those experiences as disabling, and because their experiences telling these stories have led to such violence that they cannot risk sharing them anymore.

written, verbal) and the depth to which they impact our careers and health. We speak to our own experiences as disabled people and caution readers to recognize that disabled people each have complicated and nuanced relationships with their bodymind and the circumstances of their disablement, some of which likely differ significantly from ours.

We need to talk about...

... *violence, again* || *Rua*

“It is rather difficult for [people] to handle their emotions when being around children with impaired social interaction” ... “Higher social function would be an improvement for children with autism (not to mention the potential positive impact on [their] caregivers)” ... “Differential therapies exist to attempt to lessen the [social] deficits and family distress” ... “a stepping-stone for autistic children to interact with humans.”

The excerpts above all come from ACM publications⁹. The cited studies center around the use of Socially Assistive Robots for Autism Therapy. The premise in each is that robots can be used to augment social therapies that seek to train normative social responses – training which presumably leads to an increased quality of life. However, this supposed improved outcome of normative sociality is, in each of these papers, centered around the relief such normativity will bring to a family and wider society. Autistic people are described predominantly as lacking something, having a deficit instead of acknowledging differences in communication and embodiment [13].

⁹While these are actual excerpts, we chose not to reference them directly as to not ‘call-out’ researchers, who are, essentially, a product of their own ableist environment. We focus on strong statements specifically to illustrate the repetitive aspect of such instances across a range of publication, inflicting pain over and over and over and over¹⁰again.

¹⁰And people say echolalia would be meaningless. hah.

The Judge Rotenberg Center (JRC) is a residential institution in Massachusetts where children and adults with Intellectual and Developmental Disabilities, referred to as “students” are forced to wear a Gradual Electronic Decelerator (GED). The GED is used to deliver punitive electroshock to control “undesirable behavior”. In 2014, the FDA held a hearing and determined the use of the GED was an unreasonable risk to health and should be banned, but to this day, the ban has not been put into effect. The JRC is still shocking its residents, resulting in psychological and physical trauma. [We are still waiting.](#)

Rather than explore what it is that compels society to reject the sociality of autistic people [22, 25, 34, 44], computing researchers are largely perpetuating the cultural narrative that the child must change to access society¹¹. Such a narrative puts the burden of the social stigma and exclusion faced by autistic people on the very victims of sociocultural bias — bias which can lead to death (see sidebars). What does it mean for computing researchers to continue to focus on social normativity in autism intervention? What would it mean for the field to denaturalize and delegitimize the premise that as autistic people behaving autistically, we are naturally at risk for unnatural death, and thus must be protected not from violent abuse, but from our own bodies?

I want readers to understand that when I critique the direction of research inquiry in our field, I am attempting to hold us accountable to our participants, their communities, and their future. The assumptions and frameworks we use to ground our inquiry has consequences. These consequences ripple outward, from individual interactions in the lab, to the research community, to public discourses, to individual interactions in the world. When I demand this accountability from you, it is because I hold you in the highest regard. I believe in you, in us. I believe we can do better.

During ASSETS 2019, five separate people asked me to explain what I meant when I referred to “violence” in research and the academy. A chain of memories rippled in my mind. A room of over 200 assistive technology researchers, laughing at the video of young participants, a boy’s autonomous play mocked as intractable stereotypy. A girl’s hands as they were forcibly taken by the aide to make sure she participated “in time”. A small child, cowering in a corner while a robot pursued them, an overhead

camera collecting data to train an algorithm to identify “negative” social responses. The boy in a Judge Rotenberg Center surveillance tape, begging for the shocks to stop. Max Benson, held prone, his throat too compressed to even allow him to cry for his mother. Je’Hyrah Daniels at the bottom of the Hillsborough river.

What is violence?

Building an industry on the premise that children must be normalized, shaped away from “unruly”, to prevent their own murders... I find it quite violent.

...the radar || Eva

When I was a child, dyslexia was not really known, let alone dyscalculia. I was in my 40s, when a friend suggested I might be dyscalculic, after we were joking about some of my difficulties with numbers and mental calculations¹². And indeed, even if not formally diagnosed, I recognize myself in all descriptions. Spreadsheets are a life saver, I’ll redo all calculations several times, and I’ve developed a number of workarounds so I’ll not have to deal with numbers greater than 20 in my head. . . All the time, I had the feeling that I need to disguise and hide my inability to deal with numbers, as it can feel embarrassing and requires a lot of explanation. People are incredibly unwilling to believe that somebody with my education (and somebody who studied computer science) struggles with numerical thinking and will repeatedly question whether this is true.

So, I’ve ended up frequently having to improvise and develop tricks to avoid being ‘found out’, such as delaying any calculations or getting somebody else to calculate how to split the bill... trying to remain below the radar.

¹¹Though, rare positive examples doing so, exist, e.g. [42].

¹²Please note: dyscalculia does not affect the ability for abstract math.

...collaboration

Katta: You might be interested in being involved in our alt.chi paper.

A(nonymous): Oh?

Katta: This is the premise: "I would prefer to set it around the epistemic violence that is caused on us and exemplify this through personal vignettes. Sharing this pain can be powerful and also might allow people to reflect more on how they treat us particularly as we speak as colleagues."

A: That's interesting! I am not sure if I have the courage the rest of you have in spades though. hm.

Which I guess is sort of the point.

That I, for instance, am terrified of compromising my, now less impressive as of two days ago, job opportunities by throwing myself into a fight.

Katta: That's fair. We're pondering setting up some infrastructure for anonymous vignettes.

A: I'm definitely interested, don't get me wrong... I am just terrified of my future, hehe.

... *being a problem* // *Judith*

I have ADHD. My surroundings (home and office) will forever be a mess as I rush from one idea to the next. I can never plan and prioritise: instead my day is structured by urgent emails saying my response/contribution is overdue. And please don't ask me to take notes at a meeting: I cannot multitask. Hell, on many days, I can't even task.

On the other hand, I have a huge amount of enthusiasm. I'm constantly excited by the next new thing, and I'm able to motivate and enthuse others. I can think across disciplines and bring together disparate ideas. I'm also an excellent proofreader: because concentration is such an ongoing and sustained effort, I read very slowly, word by word, picking up things that others might miss, whilst at the same time worrying that I might be missing the overall picture.

Although I don't claim to speak for anyone else with ADHD¹³ (or any other disability, for that matter), there is something that concerns me. Much of HCI research focuses on finding a solution to a "problem", typically by designing a new technology that can solve this problem, or go some way towards addressing it. This forms the introduction to most papers, and to be fair, I've often advised my PhD students to start their papers with the following points: 1. What is the problem/issue? 2. Why should you care? 3. Here's what we've done to address it.

Within such a worldview, the implicit assumption is that the worse the problem/issue, the more any solution will be noteworthy and important. And in order for people to jump through academic hoops and show that what they are doing has real value, they need to portray the issue as a real and severe one. Which is probably why, when reviewing research on ADHD within the HCI field, I came across such phrases as "*burden on society*", "*unable to make meaningful connections to other people*", "*strain on families*", "*high likelihood for criminal conduct*" and, always and persistently, "*deficits in academic performance*" (see also, above).

So we're in a bit of a Catch 22. If my colleagues acknowledge positive aspects of ADHD (or any other disability), and all of the strengths that we can bring to the table, then that diminishes the potential impact of their "solution" to a "problem", makes their work potentially less publishable, and could impact negatively on their careers.

What to do? I don't know.

...*the labour of access* // *Cynthia*

During my career, I have often done expert user or diversity work. Being a blind researcher working on projects to en-

¹³The idea that we might view any disability as some monolithic, homogeneous entity that manifests uniformly is problematic in and of itself.

hance quality of life for blind and visually impaired people with technology probably meant this was inevitable. But this work represents a spectrum from delightful to exploitative and I hope that these snippets can demystify which types of interactions should be avoided and cultivated.

For example, I've been asked to participate in studies at professional development events. During one, someone exclaimed "Do you actually know how to read braille?" when I could not complete several braille-related tasks. The phrase that was supposed to assure me, and one I repeated to my own participants, "It's not you we're testing, it's the technology", I certainly did not believe in that moment; I was ashamed. But I was also angry because I do read braille. But at the same time, I felt guilty for being angry. Additionally, braille literacy is a rare gift withheld from most blind children, so if I could not read braille, it would probably have more to do with poor education than my capabilities, and certainly more to do with education than my ability to operate a prototype. During another encounter, someone interrupted me in conversation with someone else to place their business card, which I could not read, into my hand. They wanted me to test something. I didn't. But again, the guilt. If I am fighting to not be cast a user, what of our users? I am building up the same hierarchy I disagree with.

I am now more assertive about my boundaries around meeting new people. In turn, some of my initial interactions are awkward, and these negotiations have slowed development of relationships with some remarkable researchers. I clarify that I can speak with them as a researcher; we can talk about methods, epistemologies, being academics, but I cannot give feedback on individual projects. For now, it is the trade-off I accept because I have watched people reframe their requests of me in what I hope is a realization that their seemingly innocuous ask for my time and exper-

tise feeds into ableist hierarchies (which presume I attend professional development events to act as a user) that keep my attendance a rarity in the academy.

I've gotten a handle on the expert user work. I avoid most of it now. But with that relief comes a new challenge—diversity work. Many of us are familiar; it is the work of turning what can become deep loneliness finding fewer and fewer people like you, particularly as you move up the academic ladder, into hope, hope that something you will do will raise awareness and most importantly, representation. But this work is scary. First, this work is often not even cast as such; disability is rarely part of diversity efforts. Second, I am told to not do it; it will interfere with my productivity. But my inbox greets requests for my diversity work regularly. It seems that I should care for myself until the advising mentor needs access to my expertise. And I do the same thing; I ask of others what I wish wasn't asked of me. As my demands to be treated as more-than-user downplays the importance of disabled users if it also widens how disabled people are figured in HCI, my diversity work is similarly tensioned.

What I find interesting is that many conversation partners (myself included), whether warning against or encouraging me to do, diversity work, assume that it is my choice (see also, [47]). But as our lived experiences demonstrate, if I do not name it and claim it, what I do in the hallways at conferences, during the reflections with researchers about the legitimacy of (even angry) disabled perspectives, in the lengthy education and explanations on how to do research or conduct class accessibly, I will get even less credit than the insufficient recognition offered me. Where, to some, I am immediately figured a user to some, I am also figured the diversity worker. In other words, I will be expected to do the work; I will do the work; it isn't a choice. So, if it leads to my downfall, naming it and claiming it at least makes clear

how my productivity (as if diversity could or should even be separated from productivity) is insufficient.

... *material consequences* // Katta

I have an interview for a job I am highly qualified for. The interviewer and I have good rapport. She says that I am the most aptly qualified candidate for this job. We share the same ideas about how the study programme I might teach for should look like and we share the same ideas about how this fits into research. She asks me about my specific approaches to teaching. Excitedly, I start: “Well, having ADHD myself...” and her eyes narrow “... I want to make space for different ways of learning...” one eyebrow raises “... and, uhm, so... I try to create visual markers for content and...” her eyes dart away from me towards the CV “... provide students with different options for how they might want to take their exam and...” – “So, you have ADHD?”

Within five minutes, the interview ends and we say goodbye. She assures me, I will hear from her soon, but also that there are quite a few good candidates (that did not seem to be there before). After two months, I receive a notification: “In spite of your impressive Curriculum Vitae and excellent qualifications, we regret to inform you that your profile does not fully match the requirements for the vacant position.” On my way home, I try my hardest to keep my thoughts from spiralling into self-damnation about not being able to keep my damn mouth shut.

... *how it's not all bad* // Cynthia

I began work in a lab with several researchers who respected me as a professional and most of all, as a human. I learned from senior graduate students how to do the day-in and day-out of research work. I was mentored by faculty who began to give me language and direction to grow my passion, confusion, and uncertainty into a research program. Sometimes, researchers asked me to

troubleshoot their prototype to ensure that when they recruited blind participants, they could answer the questions they hoped to answer. Sometimes, the same researchers tagged my PDF submissions because at the time, making them screen reader accessible was less possible to do with a screen reader (it is still not accessible in many circumstances). Sometimes, I advised the project, the methods, the framing of the paper. Sometimes I helped researchers build bridges to communities because of my ongoing friendships and rapport with blind people. And sometimes, I make mistakes. During one project meeting, some researchers and I contemplated whether guide-dog users would provide the information we sought to answer our research questions. We decided ‘no’. A passionate discussion on that exclusion criterion circulated on an email list of blind people. They rightfully pointed out that our recruitment was ableist and would benefit from perspectives of guide-dog users. I felt ashamed of my mistake, discussed it with the other researchers, and we eliminated that exclusion criterion and apologized. I will never repay the guide-dog users who taught me, but these stories are not meant to disappear discomfort; recognizing the complexity is an important first step. These experiences have been extremely valuable. The variety of work I have encountered, some certainly relegated to me because I am disabled, for example, seeded my dissertation which points out the ironies of our field and extractive nature of our relationships with disabled people when inclusion and accessibility fail to account for the (in)accessibility of our methods and cultures.

What now?

The vignettes illustrate a range of experiences we’ve had as disabled academics. In collating those, we often shared similarities across the conditions we embody and the literature we read. We created community in sharing our experiences within the group of authors and hope to extend that

community beyond our group, reaching out to those who cannot be with us and those who are not yet.

We could have told more stories. We could have told stories on the persistent violations of our physical boundaries, stories on our failure to be on equal footing with colleagues who hone their CV while we keep on putting in the additional labor organizing our very presence in the academy, stories on organizational structures more focused on a rhetoric of financial decisions that benefit nondisabled people more than those which may help make participation more equitable and welcoming, stories on the ways nondisabled mentors have tried to pit us against each other as the 'good' and the 'bad' crip¹⁴ and so many more stories on the sustained epistemic exploitations, often framed as a 'positive experience' for non-disabled people.

We could have told more stories. And yet, we also couldn't. Some didn't make it into this version of the paper. Because they felt too dangerous, rendered us too vulnerable, became a place for personal torment and risked marginalising us further. Until the final submission, drafts changed drastically, and comments and email threads filled with questions and fear. Stories were deleted; stories were edited specifically to remove content we believed would further threaten our careers. Part of this paper are all the untold stories.

We found that our marginalisation within academia not only requires us to be competitive within our respective fields, it ultimately requires more labour from us. Whereas most academics have the luxury of choosing whether they engage in activism, the privilege of their actions not being reflexively labeled as such, we have to continuously work additional hours to gain access to the events, pub-

¹⁴We use the term crip to "denote the desire to unsettle, to contest and challenge normalcy" [29, p.2].

lication venues, teaching support and opportunities for service work. We are tired and exhausted. And even in cases where we have done the work academically and have fought for our own access, we then still face regular ableism, such as that which increases the already high baseline precarity within the academic job market.

All the while, when reading about our conditions, we are bombarded with dehumanising content within our field. We read work framing us as incapable, as burdens to others, as unlovable, as deficient. This comes paired with the prejudiced behaviour by our colleagues through physical intrusions, epistemic exploitations, implicit and explicit dismissal and belittled pain. On top of that, we find an utter disregard for passionate engagement [26, 53], where our perspectives remain systematically silenced until we scream, upon which they are declared irrelevant due to lack of 'civility'.

As researchers researching our own condition exposes us to the painful realization of how knowledge about our conditions is constructed within technological research. We feel stripped bare, made an argument for technical solutions which reduce costs, as if our humanity is not sufficient to be considered worthy of life and love. In return, the perspectives of disabled people are actively erased in multiple ways: sometimes framed as 'personal' and 'emotional' and 'unscientific', sometimes due to a privileging of "medical expert" knowledge and carer's needs, sometimes in overt or subtle othering, sometimes in more tacit and fleeting ways. Research that fails to seek the perspectives of disabled people at all keeps being validated and published without a scrutiny towards ableist tendencies. Or, in other words, "the majority of academics do not consider disability to be part of their social conscience" [12, p32]. This epistemic violence, in terms of prioritising ableist ways of knowing and ableist research, leads to material consequences in

our acquired heightened suspicion towards non-disabled colleagues due to repeated intrusions, lack of time to increase our research portfolio due to increased efforts made in gaining access for ourselves and others, as well as less security for our livelihood given the difficulties of disclosing disability in the highly competitive academic job market.

What we ask is for nondisabled people to remove some of the questions and uncertainty from us and replace them with evidence that we are becoming your peers. For example, assume disabled people will be present, will read, review, or even chair the committee your paper is assigned. When you want to introduce someone to your disabled colleague ask why. Insure this person will come to the conversation prepared so the humanity of disabled people is not debated, and mundane disabled interactions are no longer a spectacle. When you are angry at your disabled colleagues, ask why. What are the histories and lived experiences that might make a disabled person upset? Have you read at least three disabled people who wrote about the topic on their blogs, memoirs, podcasts and academic journals? When you are given accessibility requests and believe it is unreasonable, ask why believing someone's request is unreasonable is easier than believing that person is making an honest effort to articulate what they need to access a space, instead of asking them which accommodations they should live without. When you ask someone to give their time and talents, what is one, two, three things you will change to ensure that next time you need their help, they can teach you something new instead of repeating their diversity work. How many disabled people have you recruited as participants and how many disabled people are your friends? If the latter number is lower, what are you doing to even them out? Whereas this paper explicates some ways how disabled identity is taken for granted (itself reductionist), we am still part of this harmful system.

Appreciation

This paper was partially supported by a Microsoft Ada Lovelace Fellowship, Margaret Wander and Margeret Hopkins.

These all touch on aspects of our work that are very much in progress; they represent growth from our own mistakes and accountability mechanisms to hopefully help us prevent and quickly notice future mistakes. But these are the expectations given to students and as academics, we should be nurturing the lifelong student inside all of us. This is not about arguing for or condoning a notion of censorship, we ask those researching within this space to more actively reflect how they position their research within larger systemic factors (see also, [43]). And to acknowledge that we all can always do better.

We are collectively committed to putting different works forward, works that center the perspectives of disabled people (e.g., [27]), works that propose a position of pride against prejudice¹⁵, work that is oriented at dissolving the disparities between funding structures and the research questions that are relevant to disabled people [40]. In this, we're not asking nicely for more charitable treatment, we're demanding to not be violated, epistemically or materially. Counteracting this epistemic injustice starts with questioning the disembodied and dispassionate ways we deem appropriate for knowledge production. One place where this might start is making more space for cripistemologies, "the production of knowledge about disability comes not only from being disabled but from being with and near disability, thinking through disabled sensations and situations, whether yours or your friend's" [28, p141].

Acknowledgements

We position ourselves in solidarity to those who could not dare to be co-authors. We rally here for them. We thank our fellow crip communities for their continued love and support. We weep for those of us who are not with us anymore.

¹⁵We deliberately echo the words of Jenny Morris in solidarity [35].

REFERENCES

- [1] Sara Ahmed. 2019. A Complaint Biography. *Biography* 42, 3 (2019), 514–523.
- [2] Erin E Andrews, Anjali J Forber-Pratt, Linda R Mona, Emily M Lund, Carrie R Pilarski, and Rochelle Balter. 2019. # SaytheWord: A Disability Culture Commentary on the Erasure of “Disability”. *Rehabilitation psychology* (2019).
- [3] Christine E. Ashby. 2011. Whose “Voice” is it Anyway?: Giving Voice and Qualitative Research Involving Individuals that Type to Communicate. *Disability Studies Quarterly* 31, 4 (2011). DOI : <http://dx.doi.org/10.18061/dsq.v31i4.1723>
- [4] Cynthia L. Bennett and Daniela K. Rosner. 2019. The Promise of Empathy: Design, Disability, and Knowing the “Other”. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems (CHI '19)*. ACM, New York, NY, USA, Article 298, 13 pages. DOI : <http://dx.doi.org/10.1145/3290605.3300528>
- [5] Nora Berenstain. 2016. Epistemic Exploitation. *Ergo: An Open Access Journal of Philosophy* 3 (2016), 569–590.
- [6] Lydia XZ Brown, E Ashkenazy, and Morénike Giwa Onaiwu. 2017. *All the weight of our dreams: On living racialized autism*. DragonBee Press.
- [7] Nicole Brown and Jennifer Leigh. 2018. Ableism in academia: where are the disabled and ill academics? *Disability & Society* 33, 6 (2018), 985–989. DOI : <http://dx.doi.org/10.1080/09687599.2018.1455627>
- [8] Fiona Campbell. 2009a. *Contours of ableism: The production of disability and abledness*. Springer.
- [9] Fiona A.K. Campbell. 2001. Inciting Legal Fictions-Disability’s Date with Ontology and the Abieist Body of the Law. *Griffith Law Review* 10, 1 (2001), 42–62.
- [10] Fiona Kumari Campbell. 2009b. Internalised Ableism: The Tyranny Within. In *Contours of Ableism*. Springer, 16–29.
- [11] Eli Clare. 2017. *Brilliant imperfection: Grappling with cure*. Duke University Press.
- [12] Lennard J Davis. 2002. *Bending over backwards: Essays on disability and the body*. NYU Press.
- [13] Hanne De Jaegher. 2013. Embodiment and sense-making in autism. *Frontiers in Integrative Neuroscience* 7 (2013), 15. DOI : <http://dx.doi.org/10.3389/fnint.2013.00015>
- [14] Kristie Dotson. 2011. Tracking epistemic violence, tracking practices of silencing. *Hypatia* 26, 2 (2011), 236–257.
- [15] Jane Dunham, Jerome Harris, Shancia Jarrett, Leroy Moore, Akemi Nishida, Margaret Price, Britney Robinson, and Sami Schalk. 2015. Developing and reflecting on a Black disability studies pedagogy: Work from the National Black Disability Coalition. *Disability Studies Quarterly* 35, 2 (2015).
- [16] Murray Edelman. 1974. The Political Language of the Helping Professions. *Politics & Society* 4, 3 (1974), 295–310.
- [17] Nirmala Erevelles. 2000. Educating unruly bodies: Critical pedagogy, disability studies, and the politics of schooling. *Educational theory* 50, 1 (2000), 25–47.

- [18] Michel Foucault. 1976[1975]. *Überwachen und Strafen. Die Geburt des Gefängnisses*. Suhrkamp, Frankfurt a.M., Germany.
- [19] Miranda Fricker. 2007. *Epistemic injustice: Power and the ethics of knowing*. Oxford University Press.
- [20] Dan Goodley. 2013. Dis/entangling critical disability studies. *Disability & Society* 28, 5 (2013), 631–644. DOI : <http://dx.doi.org/10.1080/09687599.2012.717884>
- [21] Donna Haraway. 1988. Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies* 14, 3 (1988), 575–599. <http://www.jstor.org/stable/3178066>
- [22] Brett Heasman and Alex Gillespie. 2019. Neurodivergent intersubjectivity: Distinctive features of how autistic people create shared understanding. *Autism* 23, 4 (2019), 910–921.
- [23] David I. Hernandez-Saca and Mercedes A. Cannon. 2016. *Disability as Psycho-Emotional Disablism: A Theoretical and Philosophical Review of Education Theory and Practice*. Springer Singapore, Singapore, 1–7. DOI : http://dx.doi.org/10.1007/978-981-287-532-7_456-1
- [24] Nick Hodge. 2014. Unruly bodies at conference. *Disability & Society* 29, 4 (2014), 655–658.
- [25] Gregory Hollin. 2014. Constructing a social subject: Autism and human sociality in the 1980s. *History of the Human Sciences* 27, 4 (2014), 98–115. DOI : <http://dx.doi.org/10.1177/0952695114528189>
- [26] Alison M. Jaggar. 1989. Love and knowledge: Emotion in feminist epistemology. *Inquiry* 32, 2 (1989), 151–176. DOI : <http://dx.doi.org/10.1080/00201748908602185>
- [27] Dhruv Jain, Audrey Desjardins, Leah Findlater, and Jon E. Froehlich. 2019. Autoethnography of a Hard of Hearing Traveler. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*. Association for Computing Machinery, New York, NY, USA, 236–248. DOI : <http://dx.doi.org/10.1145/3308561.3353800>
- [28] Merri Johnson and Robert McRuer. 2014. Cripistemologies. *Journal of Literary & Cultural Disability Studies* 8, 2 (2014), 127–148. DOI : <http://dx.doi.org/10.3828/jlcds.2014.12>
- [29] Kirsty Liddiard. 2017. *The intimate lives of disabled people*. Routledge.
- [30] Jennifer Mankoff, Gillian R. Hayes, and Devva Kasnitz. 2010. Disability Studies As a Source of Critical Inquiry for the Field of Assistive Technology. In *Proceedings of the 12th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '10)*. ACM, New York, NY, USA, 3–10. DOI : <http://dx.doi.org/10.1145/1878803.1878807>
- [31] Deborah Marks. 1999. Dimensions of Oppression: Theorising the embodied subject. *Disability & Society* 14, 5 (1999), 611–626. DOI : <http://dx.doi.org/10.1080/09687599925975>
- [32] Michele C. McDonnall and Zhen Sui. 2019. Employment and Unemployment Rates of People Who Are Blind or Visually Impaired: Estimates from Multiple Sources. *Journal of Visual Impairment & Blindness* 113, 6 (2019), 481–492. DOI : <http://dx.doi.org/10.1177/0145482X19887620>

- [33] José Medina. 2017. Epistemic Injustice and Epistemologies of Ignorance. In *The Routledge Companion to the Philosophy of Race*. Routledge, 247–260.
- [34] Damian EM Milton. 2012. On the ontological status of autism: the ‘double empathy problem’. *Disability & Society* 27, 6 (2012), 883–887.
- [35] Jenny Morris. 1991. *Pride against Prejudice: Transforming Attitudes to Disability*. The Women’s Press, Toronto.
- [36] Ingunn Moser. 2006. Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal. *Information Communication and Society* 9, 3 (2006), 373–395. DOI : <http://dx.doi.org/10.1080/13691180600751348>
- [37] Aparna Nair. 2019. “Like Bananas with Brown Spots”—Epilepsy, Embodiment, Vulnerability and Resilience in South Asia. *Canadian Journal of Disability Studies* 8, 4 (2019).
- [38] Karen Nakamura. 2013. *A disability of the soul: An ethnography of schizophrenia and mental illness in contemporary Japan*. Cornell University Press.
- [39] Joyojeet Pal. 2017. CHI4Good or Good4CHI. In *Proceedings of the 2017 CHI Conference Extended Abstracts on Human Factors in Computing Systems (CHI EA '17)*. Association for Computing Machinery, New York, NY, USA, 709–721. DOI : <http://dx.doi.org/10.1145/3027063.3052766>
- [40] Elizabeth Pellicano, Adam Dinsmore, and Tony Charman. 2014. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism* 18, 7 (2014), 756–770. DOI : <http://dx.doi.org/10.1177/1362361314529627> PMID: 24789871.
- [41] Therí Alyce Pickens. 2019. *Black Madness :: Mad Blackness*. Duke University Press.
- [42] Kathryn E. Ringland, Christine T. Wolf, Heather Faucett, Lynn Dombrowski, and Gillian R. Hayes. 2016. “Will I Always Be Not Social?": Re-Conceptualizing Sociality in the Context of a Minecraft Community for Autism. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA, 1256–1269. DOI : <http://dx.doi.org/10.1145/2858036.2858038>
- [43] Jennifer A. Rode. 2011. Reflexivity in Digital Anthropology. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '11)*. Association for Computing Machinery, New York, NY, USA, 123–132. DOI : <http://dx.doi.org/10.1145/1978942.1978961>
- [44] Noah J Sasson, Daniel J Faso, Jack Nugent, Sarah Lovell, Daniel P Kennedy, and Ruth B Grossman. 2017. Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific reports* 7 (2017), 40700.
- [45] Sami Schalk. 2018. *Bodyminds Reimagined:(Dis)ability, Race, and Gender in Black Women’s Speculative Fiction*. Duke University Press.
- [46] Jackie Leach Scully. 2018. From “She Would Say That, Wouldn’t She?” to “Does She Take Sugar?” Epistemic Injustice and Disability. *IJFAB: International Journal of Feminist Approaches to Bioethics* 11, 1 (2018), 106–124.

- [47] Katta Spiel. 2020. My Activism isn't a Choice. (2020). <https://medium.com/@kattaspiegel/when-activism-isnt-a-choice-7b2e0d611d38>
- [48] Katta Spiel, Christopher Frauenberger, Eva Hornecker, and Geraldine Fitzpatrick. 2017. When Empathy Is Not Enough: Assessing the Experiences of Autistic Children with Technologies. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 2853–2864. DOI : <http://dx.doi.org/10.1145/3025453.3025785>
- [49] Katta Spiel, Christopher Frauenberger, Os Keyes, and Geraldine Fitzpatrick. 2019. Agency of Autistic Children in Technology Research—A Critical Literature Review. *ACM Transactions on Computer-Human Interaction* 26, 6, Article 38 (Nov. 2019), 40 pages.
- [50] Katta Spiel, Laura Malinverni, Judith Good, and Christopher Frauenberger. 2017. Participatory Evaluation with Autistic Children. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17)*. ACM, New York, NY, USA, 5755–5766. DOI : <http://dx.doi.org/10.1145/3025453.3025851>
- [51] Gayatri Chakravorty Spivak. 1988. Can the subaltern speak? Marxism and the interpretation of culture. *Urbana: University of Illinois Press* (1988), 271–313.
- [52] Rua M Williams. 2019. Metaeugenics and Metaresistance: From Manufacturing the 'Includeable Body' to Walking Away from the Broom Closet. *The Canadian Journal of Children's Rights* 6, 1 (2019).
- [53] Rua M. Williams and LouAnne E. Boyd. 2019. Prefigurative Politics and Passionate Witnessing. In *The 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '19)*. ACM, New York, NY, USA, 262–266.
- [54] Rua M Williams and Juan E Gilbert. 2019. "Nothing About Us Without Us" Transforming Participatory Research and Ethics in Human Systems Engineering. In *Advancing Diversity, Inclusion, and Social Justice Through Human Systems Engineering*, Rod D. Roscoe, Erin K. Chiou, and Abigail R. Wooldridge (Eds.). CRC Press, Cleveland, OH, USA, chapter 9.